



MDI News Update

Issue 31 – Two monthly newsletter – January 2007

**Muscular Dystrophy Ireland, 71/72 North Brunswick Street, Dublin 7.
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Editorial

Hello Everyone,

Happy New Year! A new year and a new look! As you can see, our newsletter has gone colour. Hope you like it.

In this issue:

Our Research page gives details on where to get updates on DMD research along with details of an Information Day on 10th March on the topic of “management of muscular dystrophy”.

Our Awareness Day 2007 is fast approaching and once again we need your support. More details on page 3.

Most of you are probably aware of the changes in last December’s budget which affect you. To be sure you’ve missed nothing, I’ve included a brief summary on page 5.

On 13th December 2006 the UN adopted a landmark disability convention, which has been described as the “dawn of a new era” for people worldwide living with disabilities. See page 6 for more.

With details and photographs of recent MDI functions also included, hopefully there’s something to interest everyone.

The next issue of this newsletter is due out in March 2007. I’m already looking for articles etc. so until next time, happy reading and get writing!

Slán.

Hubert McCormack
Editor

PLEASE SUPPORT
Muscular Dystrophy Ireland
NATIONAL AWARENESS DAY



See page 3 for more information on how you can help!



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Research News

Summary of New Duchenne Research Results

Dr. Guenther Scheurbrandt, who regularly produces reports about research into Duchenne muscular dystrophy for families, has just produced a new report. Research is progressing quite speedily, so Dr. Scheurbrandt decided to write a new report on developments since July 2006.

The report includes developments in exon skipping research, gene transfer, PTC124 research, stem cell research, research into the upregulation of utrophin and into the inhibition of myostatin.

If you would like to receive a copy of this report, please contact Karen Pickering on 1800 245 300 or email karen@mdi.ie and I will send you a copy by email or in the post. You can also send your email address directly to Dr. Scheurbrandt at gscheurbrandt@t-online.de and he will add you to his mailing list so you can receive any future reports.

MDI Information Day Save the Date!

MDI is holding an Information Day on Saturday 10th March 2007 and all members are invited to attend. It will take place in the Red Cow Moran Hotel, Dublin, and will focus on the management of muscular dystrophy. Speakers on the day will include Professor Richard Costello, Consultant Respiratory Physician from Beaumont Hospital and Dr. Colin McMahon from the Cardiology Department in Our Lady's Hospital for Sick Children, Dublin.

Further details and an agenda for the day will be issued closer to the date.

*Karen Pickering
Information Officer*

ACCESS & MOBILITY

EXHIBITION 2007

When: Friday, 9th February 10:00am - 5:30pm

Saturday, 10th February 10:30am - 5:00pm

Where: Shelbourne Hall, RDS, Dublin 4

**ADMISSION
IS FREE**



For further information, please visit www.accessandmobility.ie

E-mail: info@accessandmobility.ie



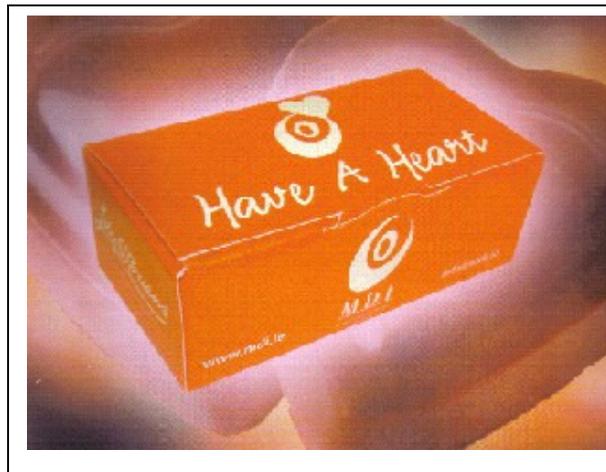
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MDI National Awareness Day 2007 14th February Valentine's Day

MDI's National Awareness Day Campaign for 2007 is now well under way and as in previous years, the main feature of this campaign focuses on the selling of heart shaped chocolates on Valentine's Day, 14th February 2007. This year Spar shops nationwide will once again be selling our chocolates and everyone who purchases just one small box for €2.00 will also have the option of entering into a free draw to win a Budget Travel Summer Holiday to Majorca for 2 Adults for 1 week.

As before, the purpose of our Awareness Day is twofold: firstly, to raise money for MDI to help fund some of the various support services which we provide to our members and secondly but equally as important, to create further awareness of the condition muscular dystrophy.



Once again MDI are seeking the support of our members and friends alike to help build on the success of last year's campaign by offering to sell chocolates and/or encouraging commercial outlets such as shops, hotels, restaurants etc. to purchase cartons of our chocolates to sell or distribute amongst their customers, perhaps as a complimentary gift for Valentine's Day. Each carton consists of 60 units of two heart-shaped Lily O'Brien's chocolates in attractive new small red boxes which will be sold for €2.00 each.

MDI would really appreciate any support which members can give in helping to make our Awareness Day Campaign for 2007 an even greater success than last year. Perhaps you could take some chocolates sell amongst your colleagues in work or in your local pub, club, school, etc.

We would really appreciate your support.

For more information contact **Steven Valentine** in the MDI office on 1800 245300 or email: steven@mdi.ie

MDI would like to thank the following for supporting our Awareness Day 2007:





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Eurordis Photography Competition 2007

Following the success of its 2006 Photography Competition, Eurordis has once again launched a similar competition for 2007. This year the competition is open to anyone who has an interest in rare diseases in Europe. The closing date for receipt of entries is: 31st March 2007.

Only digital photos are accepted. You can submit up to five photos.

Winning entries will be exhibited at the Eurordis 2007 Membership Meeting in Paris on 4/5 May and posted on the Eurordis website. Prizes will be awarded to the best picture per category.



Categories and prizes are as follows:

Category: *Portrait of the person affected by a rare disease:*

Prize: *Personal Digital Assistant (PDA)*

Category: *Rare disease patients in the medical environment (hospital, clinic, at the doctor's, etc):*

Prize: *GPS Navigator (with European map)*

Category: *Recreational activities for people affected by rare diseases (summer camps, recreation programmes, weekends away etc):*

Prize: IPOD

Category: *Rare disease patients with friends, family and people not affected by rare diseases:*

Prize: Digital camera

For more information visit the EURODIS

Website:

http://www.eurordis.org/article.php3?id_article=916

Student Needs Your Help!

Catherine Hitchcock is a third year student at D.I.T. Mountjoy Square in Dublin, studying Social Care. She has to complete a thesis and is now looking for members of MDI who would be willing to help. Catherine's thesis is "Positive and negative effects of having a disabled member in the family on both the parents and the siblings". You can help Catherine by taking part in a short interview with her. This involves answering a few questions about the experiences of having a person with a disability in the family, and can take place face to face or over the phone.

Catherine is already familiar with many of the issues families face and with the work of MDI, since she had a brother with muscular dystrophy herself.

If you would like to help Catherine with her thesis or would like to know more about it, you can contact her on: 0876966460 or Email at: hitchcockcatherine@yahoo.ie



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Budget 2007

Most of you are probably aware of the changes in last December's budget which apply to you directly. However, to ensure that you are aware of all these changes, we have included the following article which outlines a summary of the specific changes in relation to individual entitlements in Budget 2007 pertaining to disability, which were announced by Minister Brian Cowan last December. For further information or to ensure you are in receipt of all entitlements contact your local Citizens Information Centre or visit: www.citizensinformation.ie

Services for persons with a disability / National Disability Strategy

Budget changes affecting people with disabilities are made in the context of the National Disability Strategy which promotes greater co-operation between departments in the planning and delivery of services for people with disabilities.

Social welfare

New maximum rate of Disability Allowance and Blind Pension: €185.80 per week (January 2007)

Entitlement to the full rate of Disability Allowance extended to all qualified persons resident in institutions (January 2007)

The amount of capital disregarded from the means test for Disability Allowance increases from €20,000 to €50,000 (June 2007)

Invalidity Pension increased to €191.30 (aged under 65).

Occupational Injuries Benefits Disablement Pension increases to €216.90 per week

Respite Care Grant increases to €1,500 (June 2007)

Tax

Incapacitated Child Tax Credit increases to €3,000 (January 2007)

Blind Person's Tax Credit increases to €1,720 (single) and €3,520 (married, both spouses blind).

There are to be improvements in the administration of claims for tax refunds for medical expenses.

Older people

State Pension (Non-Contributory) and Carer's Allowance for people aged over 66 will increase by €18 a week.

State Pension (Contributory) and other insurance-based payments for people of pension age will increase by €16 a week. The employment earnings disregard for State Pension (Non-Contributory) will increase to €200 per week.

There is a 10% increase in the age tax credits.

The tax exemption limits for people aged over 65 are increased by €2,000 for single people and €4,000 for married couples.

People who are eligible for a DIRT refund will receive this automatically.

The Qualified Adult Allowance for people aged over 66 is increased by €23.70 and is to be paid directly to the qualified adult.

The Telephone Allowance Scheme will be extended to include mobile phones.

The Companion Free Travel Pass is extended to people aged 66 to 74 who are certified as medically unfit to travel alone.



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UN urges speedy ratification of new convention described as a ‘dawn of a new era’ for people with disabilities.

On 13 December 2006 the UN General Assembly adopted a landmark disability convention, the first human rights treaty of the twenty-first century and one that United Nations Secretary-General Kofi Annan said represents the “dawn of a new era” for around 650 million people worldwide living with disabilities.

Mr. Annan, along with Assembly President Sheikha Haya Rashed Al Khalifa and other UN officials, as well as members of civil society that lobbied for the pact, urged all 192 Member States to quickly ratify the convention, which covers rights to education, health, work and a raft of other protective measures for people with disabilities.

“This promises to be the dawn of a new era – an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long. This Convention is a remarkable and forward-looking document,” Mr. Annan said in a speech read out by Deputy Secretary-General Mark Malloch Brown.

The Assembly adopted the Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities in a vote by consensus.

“In three short years, the Convention became a landmark several times over: it is the first human rights treaty to be adopted in the twenty-first century; the most rapidly negotiated human rights treaty in the history of international law; and the first to emerge from lobbying conducted extensively through the Internet”. Mr. Annan went on to urge all governments to start by

ratifying, and then implementing this treaty, without delay.”

Sheikha Haya echoed this call, adding that by adopting the Convention, Member States were sending a “clear message of solidarity” by reaffirming the dignity of all humankind and recognizing that “all societies stand to benefit from empowering this important community.”

“I look forward to the full implementation of the convention by Member States, with the involvement of all concerned parties. In particular, the NGOs (non-governmental organizations) and civil society groups whose energy, compassion and willingness to work in the spirit of cooperation greatly contributed to the final agreement.”

High Commissioner for Human Rights Louise Arbour added her voice to calls for ratification, with her office (OHCHR) noting that the agreement – which comprises 50 articles – fills a major gap in international human rights law.

“The convention... marks a historic step in ensuring that persons with disabilities enjoy full participation in society and can contribute to the community to their full potential. Speedy ratification... will end the protection vacuum that has, in practice, affected persons with disabilities,” said Ms. Arbour.

The convention provides that States which ratify it should enact laws and other measures to improve disability rights, and also abolish legislation, customs and practices that discriminate against persons with disabilities. It will be open for signature and ratification on 30 March 2007, and will enter into force after it has been ratified by 20 countries, the OHCHR said.

MDI welcomes the announcement of this new convention on the rights of persons with disabilities, which recognizes that disability is a human rights issue. We look forward to the day when all people with disabilities can enjoy full participation in society in the same way as our non-disabled counterparts and hope for a speedy ratification process.



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Branch News

MDI Galway Branch Christmas Party 2006

On Sunday 10th December, the Western Branch of MDI held their Christmas Party in the Clybaun Hotel in Salthill, a little different from previous years because it wasn't just for the Galway members but also for those in Mayo and Roscommon. The day was well attended and the children present brought a magical atmosphere to the festivities, with their energy, laughter and dancing. With a DJ who played great upbeat music and songs and Irish Dancing by two small girls, the entertainment was just brilliant.



Eileen Gormley pictured dancing with a young member at the Christmas party in Galway.

Of course the man of the moment, Santa arrived with gifts for all the children. It was beautiful to see the reaction of their faces when they

received their presents, and the adults weren't left out either, we also had spot prizes throughout the day.

It was a high-spirited, marvellous day which was thoroughly enjoyed by everyone, many thanks to Lisa and Aisling for organising this party.

Eileen Gormley
MDI Member, Galway



Hilary, Eoin & David Kiely pictured at the Galway Christmas Party

REMINDER

MDI would like to thank everyone who supported us in our recent sale of Christmas cards. Your support is much appreciated. If you have not yet returned the proceeds, we would be grateful if you could do so at your earliest convenience.

THANK YOU



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MDI North East Branch

Christmas Party 2006

Pictured on the right are three generations of the Moore Family enjoying the Christmas Party which was held at the Lakeside Manor Hotel, Virginia, Co. Cavan on 9th December 2006. Back Left brothers Ronan, Thomas and Peter. Front row, sister Karen and their Mum Una & Karen's son Shane.



MDI Dublin Branch

Christmas Party 2006

The Dublin branch held their annual members Christmas party on Sunday 3rd December 2006 in Moran's Red Cow Hotel on the Naas Road. A great day was had by all who attended, over 90 people in total, which was fantastic! The photographs below capture the day. Happy New Year to all our members!

Picture Details:

Right: Kevin & Maureen Fitzsimons.

Below: Emma Murray with Santa!



Right:

Mary, Andrew & Eamon Nolan and Sean McGonigle

